

**National Respite Coalition  
on behalf of the Lifespan Respite Task Force  
Independent Aging Agenda Event  
Post-Event Summary Report**

**Event Name:** *Lifespan Respite Summit: A Congressional Briefing*

**Date of Event:** June 17, 2005

**Location of Event:** U.S. Capitol, Washington, DC

**Number of Persons Attending:** Approximately 50

**Sponsoring Organizations:** National Respite Coalition on Behalf of the Lifespan Respite Task Force, Association of University Centers on Disabilities, American Psychological Association, National Association of State Directors of Special Education

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**Priority Issue: Respite for Family Caregivers Across the Lifespan**

According to the National Alliance on Caregiving's recent national survey, 44 million caregivers are providing care for individuals over age 18 with disabilities or chronic conditions. Most of these caregivers are already members of the baby boom generation or members of the aging population who are caring for parents, spouses, other relatives, and in increasing numbers, adult children with lifelong disabilities. All are at higher risk of poor health, failed marriages, lost income, and emotional and physical stress. Some even face higher mortality rates.

Carrie Howland, the mother of a seriously ill child, spoke to the devastating effects of constant caregiving: "I recall begging for some type of in-home support...It was during this period when I fell asleep twice while driving on the Massachusetts Turnpike on the way to appointments at Children's Hospital. The lack of respite...put our lives and the lives of everyone driving near me at risk." *Lifespan Respite Summit, 2005*

Currently, nearly 18 million children under 21 with disabilities are in families that need and rely on respite and will continue to do so after their children reach age 21. However, for many of these families, their children will age out of the system and lose many of the services, such as respite, that they currently receive. In fact, 46% of State Units on Aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities. As the baby boom generation ages, these numbers will only increase. A New Jersey parent who spoke at the Lifespan Respite Summit worried about her own future: "Presently, I come before you as a mother of a 12 year-old with a disability, in two years I will be a mother of an adolescent with a disability, in 7 short years I will be a mother of an adult with a disability, and if the present programs continue unchanged I will probably have access to even fewer respite hours than I have now."

In addition to the current shortage of respite for adult children with disabilities, we must consider the young children in caregiving situations. Aging adults are increasingly finding themselves still caring for young

children with and without disabilities. Over two million children are being cared for solely by their grandparents -- an increase of 53% just since 1990. In 2003, Harvard University researchers found a 55 percent greater risk of heart disease among grandmothers who care for their grandchildren and attributed it to greater stress and limited time for regular health-care checkups, exercise, and other habits of a healthy lifestyle.

Survey after survey has shown that respite is often the most requested family support service. Respite has been shown to improve family functioning, preserve marriages and help prevent abuse and neglect. Respite has also been shown to help avoid or delay more costly out-of-home placements, including nursing home stays and foster care, yet respite for all age groups remains in critically short supply.

Bill James, the parent of a 27 year old daughter with multiple disabilities from Arlington, TX, in discussing the situations of Arlington families said, "Most parents and families of this generation want to care for their special needs children in their home, in their community and with their families...However, when families begin feeling the chronic financial and emotional stress associated with the daily care of a nonverbal, self-abusing child who requires 24 hour care, families and marriages begin falling apart.... Can you imagine being 60 to 70 years old with medical needs of your own and without the energy of your youth trying to care for someone in the above situation? The stress can be tremendous, and before the caregiver is overwhelmed, they need relief. Respite care can rescue these families." *Lifespan Respite Summit, 2005*

### **Barriers**

In the NAC survey, two in three family caregivers said they needed help or information. The most frequently reported unmet needs were reported as finding time for myself (35%) and managing emotional and physical stress (29%), yet only 5% of caregivers said they use respite -- the very service that would help them address their unmet needs. This suggests that significant barriers remain to respite care accessibility and use.

State and federal programs may list respite as an allowable service, but no single state or federal program mandates respite as its sole focus to ensure quality, choice, capacity, start-up, and coordination or to address basic accessibility and affordability issues. As a result, the capacity for existing respite programs and providers to meet the need has far exceeded the demand. For all age groups and disabilities, quality respite options are in short supply, inaccessible or unaffordable.

Eugenia Gore, the mother of a 12 year old with autism, was told by the NJ Department of Developmental Disabilities that "my request (for additional respite) was denied because I was not a single mother, I was not at poverty level, I wasn't suffering from any mental problems, and I only had one child with a disability...Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service." *Lifespan Respite Summit, 2005*

Barriers to improved, accessible and additional respite services include:

- Lack of a policy or program focus on building coordinated respite systems;
- Too few qualified and well-trained respite workers and volunteers;
- Limited or no adequate training opportunities or orientation for providers;
- No, limited or capped funding;
- Competition for limited resources that often pits one age or disability group provider against another;
- Restrictive income, age and disability-related eligibility criteria for existing respite programs;
- Difficulties families face in navigating local, state and federal systems to find the services;

- No or extremely few respite programs, services or providers for individuals who are not Medicaid eligible or who have certain conditions, such as MS, ALS, traumatic brain injury, cancer, emotional or mental health conditions, and others.
- Exceedingly variable quality of available and appropriate respite services, not only from state to state, but from program to program.
- Limited respite options or insufficient respite hours for in-home and out-of-home care, especially for both planned and emergency respite services during nights and weekends;
- Limited or no choices of providers families prefer, even during weekday 9-5 hours; and
- Lack of coordination of resources and serious service fragmentation that leads to duplication and inefficient and wasteful delivery of services.

## Solutions

- **Enact and fully fund the Lifespan Respite Care Act (HR 3248; S. 1283) to establish State coordinated community-based systems of respite care for all family caregivers, regardless of age or disability, to recruit and train respite workers and volunteers, and to provide a range of planned and emergency respite services and options.**

Over 180 national, state and local organizations representing all age groups and disabilities have endorsed the bill. The legislation is based on model State Lifespan Respite programs which are successfully meeting families' respite needs across the Lifespan in Oregon, Nebraska, Oklahoma and Wisconsin. As respite needs and barriers should not be considered in an age vacuum, neither should the solutions. By improving respite for all ages and disabilities and coordinating responses, as in the Lifespan Respite States, resources can be shared, respite providers pooled, administrative bureaucracy reduced, and available quality respite options increased. At the Lifespan Respite Summit, reports were received directly from Lifespan Respite Programs in Nebraska, Oklahoma and Oregon.

## Nebraska

State Senator Dennis Byars (R-NE), the author of the legislation establishing the Nebraska Lifespan Respite Network, described the value of the program after only one year of having the program in place. A survey of family caregivers receiving respite was conducted by the Munroe-Meyer Institute at the end of 2000. Caregivers were identified from a diverse group of state programs ranging from Early Intervention, the Foster and Developmental Disabilities Program, and the Medically Handicapped Children's program to the Aged and Disabled waiver, the Nebraska Alzheimer's Association and the Area Agencies on Aging. Almost twice as many caregivers of family members over 21 as compared to caregivers of family members under 21 indicated the likelihood of out-of-home placement without respite support. 63% of the families with family members over 21 reported they were more likely to place their family member in out-of-home placements if respite services were unavailable. As we know, prevention or postponement of out-of-home placement ultimately reduces overall caregiving costs for the family, for Medicaid and for third party payers.

In this survey of a sampling of NE's family caregivers, respite was also shown to reduce stress and feelings of isolation, the precursors to poor caregiver health and in extreme cases, even abuse or neglect. One half to two-thirds -- 58% of the families with children under 21 and 65% of the caregivers with family member over 21 -- reported decreased isolation once respite services were available. 10% of families with children under 21 indicated that a divorce was directly related to their caregiving responsibilities and respite helped in improving their relationship with spouses and other family members.

Initially, Lifespan funds appropriated by the legislation were used to set up the structure for a statewide respite system. Since then, the NE State Legislature has seen the success of the effort and appropriated additional funds to expand the Respite Subsidy program to help families pay for respite. The Respite Subsidy across the

Lifespan is available to families who do not qualify for any other respite services. Families choose their own providers and set their own schedules. State funds are also used to expand new respite services in each Service Area.

The six regional networks recruit respite providers, offer training for providers and consumers, provide information and referral, market availability and need for respite, and match families with appropriate respite providers. Nearly 1400 new respite providers have been recruited since the program began. Network coordinators meet regularly with Medicaid Service Coordinators from the HHS System, and with representatives from Development Disabilities, Area Agencies on Aging, Independent Living Centers and the Early Development Network to identify gaps and barriers and to recruit providers as needed.

The networks can identify where the specific gaps in respite occur in their communities and address that need. For example, in the southwestern service area, special respite was established for families caring for someone with behavior disorders, emotional disturbances or mental illness. In the Central and Northern Service areas, the lifespan networks collaborated with the Alzheimer's Association in 2004 to provide over 50 hours of respite.

The Eastern Area of the Nebraska Respite Network in collaboration with the Area Office on Aging assisted 15 family caregivers in receiving financial assistance for respite during the last fiscal year. All of these families were caring for women with high levels of care needs. The Lifespan network determined that if all the 15 family caregivers that received funding for respite had placed their loved ones in a nursing facility, just for the requested respite time, the needed financial assistance would have total \$23,410. In using in-home respite, volunteers and other family members to give the needed break, the total finance assistance for 15 family caregivers to give them the respite they requested, was less than half that amount. Respite is often described as an opportunity to give the family caregiver a short break. The needs of these 15 caregivers were more involved -- they needed time to work, to care for other family members, or had serious health issues of their own that needed to be addressed.

### ***Oklahoma***

Rose Ann Percival with the Oklahoma Respite Resources Network presented at the Lifespan Respite Summit. The Oklahoma Respite Resource Network relies on an already existing statewide resource and referral system (OASIS) to link families to the program, to respite services and to training opportunities. The Network is a collaboration of 34 partners including three public agencies (DHS, Health Department and Mental Health), caregivers, advocacy agencies, private foundations and providers. This network has redirected almost \$1.8 million in public and private funds to respite care in Oklahoma and is able to serve families across age and disability categories. The State's Family Caregiver Support Program is one of the networks most vital and supportive partners, having contributed about \$1 million of redirected funds to go directly to family caregivers of the aging population to help them pay for respite.

Ms. Percival stressed how the network was built on family support principles. Caregivers are given vouchers to purchase respite care from anyone they choose and negotiate the rate of pay. This can be another family member, friend, next door neighbor, day care center, home health agency, or a private provider. A survey completed in August of 2003 for the Oklahoma Respite Resource Network showed that 85% of the caregivers chose a respite provider from within their own natural support system.

If families need help in finding a respite provider, or finding out what programs they might be eligible for, they can turn to the Oklahoma Respite Resource Network. If a family desires training for a respite provider of their choosing, the state will provide that as well. The Oklahoma model has flexible funding, so the state can find the most cost effective way to deliver services, and allow caregivers control over resources.

This program currently serves approximately 2200 caregivers. For the past 4 years the average cost for the respite vouchers has been between \$5.62 and \$5.87 per hour, compared with \$12.80 to \$26.50 per hour if the caregiver had chosen a provider from a private/public agency. This program has proven that caregivers are much more cost efficient with the resources and that respite is a cost effective way to meet the needs of caregivers. In Oklahoma, caregivers are eligible for \$400 in vouchers every three months. In our survey, 47.7% of the caregivers said this amount was adequate to meet their needs; 52% said they could use more, but added that they needed just another \$100. This means that \$1600-\$2000 per year would meet the needs of 97.7% of the caregivers in Oklahoma.

In a survey conducted by the Oklahoma Respite Resource Network, 88% of caregivers agreed that respite allowed their loved one to remain at home, 98% of caregivers stated that respite made them a better caregiver, 98% of caregivers said respite increased their ability to provide a less stressful environment, and 79.5% of caregivers said respite contributed to the stability of their marriage.

**Oregon** was the first state to implement a Lifespan Respite Program in 1997. The Director of the Oregon Department of Human Services (DHS) is charged by state law to develop and encourage statewide coordination of respite care services. The Department works with community-based nonprofits, businesses, public agencies and citizen groups to identify gaps in services, generate new resources and develop community programs to meet the needs. The Program offers technical assistance, works directly with Lifespan networks, and promotes the state respite agenda. All of Oregon's counties are currently served. AAA's throughout the state are part of the Lifespan Network. As one family caregiver wrote in a compilation of letters entitled "Lifespan Respite: Stories from the Heart of Oregon," that Ms. Girard shared at the Summit, "Within a year's time, I became the sole caregiver to three people. First, my son, with a closed head injury; second, my mother who suffered a stroke and uses a walker; and her long time friend, age 85, that's in kidney failure with Alzheimer's disease. Lifespan Respite matched our family with a qualified respite provider and Rogue Valley Council of Government through the Older American's Act Fund paid for those respite services." Dozens more letters attest to the value of collaboration and coordination to provide respite services in Oregon.

- **Increased funding for National Family Caregiver Support Program, Home and Community-Based Medicaid Waivers, Social Services Block Grant, Administration on Development Disabilities Family Support Program and others.**

Respite currently is only an allowable service under these and other federal programs and there are no requirements to recruit and train providers, increase respite capacity, improve quality, or ensure accessibility. Under these program authorities, respite is not mandated to be built upon, provided or improved. Increased funding for these programs will help encourage states to use at least some funds for respite and every respite dollar is critically needed. However, without a federal program, such as Lifespan Respite, that focuses on respite and encourages state coordinated respite systems, separate categorical respite solutions for family caregivers by age or disability will contribute to the duplication and fragmentation of respite resources for all family caregivers.